TRIO

Adult education on digital, health and data literacy for citizen empowerment

Improving digital, health and data skills - Online healthcare | Health Records: Usage and data security

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ABOUT THIS PUBLICATION

This report summarises the results of the research activities carried out in Portugal, The Netherlands, Spain, Romania and Germany within the Erasmus+ project **TRIO: Adult education on digital, health and data literacy for citizen empowerment** (cooperation partnerships in adult education programme under grant agreement no. KA220-ADU-000033817.). More information is available at **https://trioproject.eu/**.

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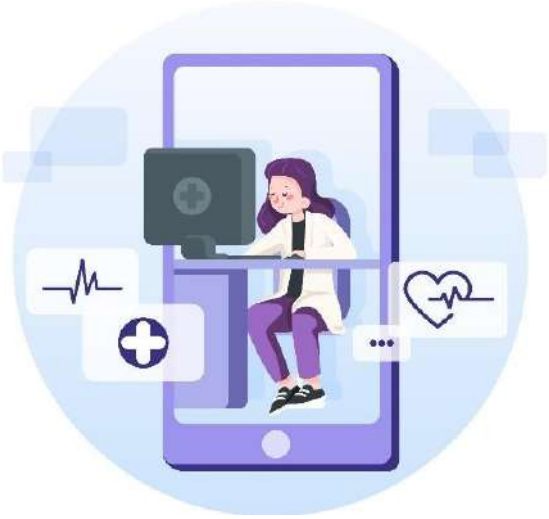
TABLE OF CONTENTS

1. Improving digital, health and data skills

1.1 Online healthcare

What is Tele-health?

In recent years, tele-health services have become more widely used by healthcare providers. ***Tele-health****, also known as telemedicine, is the delivery of healthcare services using technology, such as video conferencing, mobile applications, and remote monitoring. In this chapter you will get an overview on the different types of tele-health and how you can make use of these services yourself.*



Advantages and Barriers of Tele-health

With tele-health, you can have virtual consultations with healthcare providers from the comfort of your own home, which brings advantages and disadvantages like:

+ Saving time and Money, no need for travel and waiting in crowded waiting rooms.

+ Bridging the gap for patients in rural or underserved areas where many communities lack access to healthcare services.

+ Being available 24/7, allowing you to access healthcare services whenever you need them.

- Not all medical examination can be done online. For some medical conditions a full physical check-up is necessary.

- Digital skills are needed. A reliable internet connection and experience in using devices such as computers or smartphones are needed.

- Potential privacy and security concerns. It is important to ensure that all tele-health services meet the necessary privacy and security standards to protect patient data.

! it is important to note that not all medical examinations can be done online. It is wise to speak to your healthcare provider to check if tele-health offers fit your specific medical needs. Keep in mind that it's always a good idea to have a backup plan for in-person care.

What types of tele-health exist and where they are applied

Due to the Covid-19 pandemic and a growing shortage of healthcare professionals and staff, a lot of healthcare systems are rapidly digitalised and offer increasingly more tele-health solutions. Now, there are several different types of tele-health available, which can be used for different needs. For an overview, see the list below:

Tele-consultation is a remote medical visit where patients and doctors communicate with each other using a video conferencing tool. Patients can discuss their symptoms and medical history, and doctors can make diagnoses, prescribe treatments and give medical advice. You can find instructions for using tele-consultation on the next page.

Tele-monitoring is the use of medical devices to monitor patients remotely. For example, patients with chronic conditions such as diabetes or high blood pressure can measure their blood sugar or blood pressure levels at home. Their doctors can see the results and adjust their treatment.

Tele-psychiatry is the delivery of psychiatric care via tele-health technologies. Psychiatric patients can receive evaluations, counselling and therapy via video or telephone, which is especially useful for those in rural or remote areas who may not have easy access to psychiatric care. There are also tele-psychiatry apps available (see chapter §**Erro! A origem da referência não foi encontrada.**).

Tele-rehabilitation involves tele-monitoring and guidance for patients recovering from injury or surgery. Physiotherapists or occupational therapists can provide exercises and therapy instructions via video, telephone or text and track patients' progress with devices like smartwatches.

Tele-medicine emergency care involves the remote care of patients in emergency situations, where doctors or medical professionals can give first aid or emergency treatment instructions via video or telephone before or while the patient is taken to the hospital.

How to use Tele-consultation

Tele-consultation is a way to get medical advice from your doctor via the internet. This can be through e-mail, chat, or video calls. Tele-consultation offers a practical way to access health services from home.

Here are three easy steps for consulting your doctor online:

STEP 1 - Find a tele-consultation provider. So how do you get in contact with a doctor via tele-consultation?

Many GPs use a medical portal. This is a secure website where you can find health information, view your medical history, and order refills of your prescription. You can also use a medical portal to make appointments, either online or in person. And in some portals you can send text messages to your doctor. So ask your GP if he or she uses a medical portal and how to access it. Often this is also indicated on the website of your GP.

Do you want to try tele-consultation in your country? Try out the links below:

https://doktor.de/

https://home.mijngezondheid.nl/

https://www.sns24.gov.pt/servico/teleconsulta/

https://www.reginamaria.ro/clinica-virtuala/

https://www.medlife.ro/medlive/

https://clinica.medicentrum.ro/medicii-nostri/

https://www.europapress.es/murcia/noticia-sistema-teledermatologia-sms-evita-desplazarse-especialista-55-ciento-pacientes-20220404135542.html/

STEP 2 - Check the technical requirements. Before booking your appointment through your GP or a tele-consultation platform, first check that you have the right set-up. You will need the following things for a tele-consultation:

A **good internet connection** so you can run a video call.

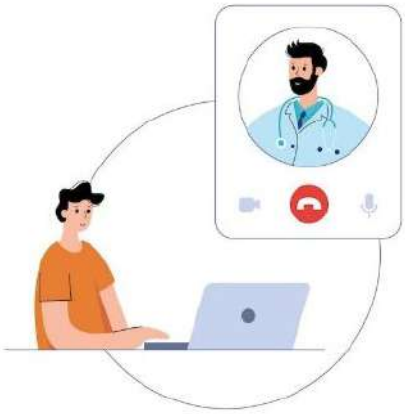
An IT device, such as **a computer, a tablet, or a mobile phone**.

A method for getting into contact with your doctor. Normally a **video call** is the best option, as visual exchange is of great value for explaining symptoms and making diagnoses.

In the table below you will find a selection of applications for video calls you can use. Always check which digital technologies are available to you and your doctor before you book an appointment.

Internet applications for using video calls

- Zoom video call - https://www.zoom.us/nl
- Go to Meeting - https://www.goto.com/nl
- Skype - https://www.skype.com/nl
- Microsoft Teams - https://teams.microsoft.com/nl



STEP 3 - Prepare for the appointment. After finding the right technology and making an appointment with a doctor, preparation is the key to a successful consultation. Below you will find two points to consider when preparing for an online consult:

(1) First of all, consider your personal needs before the meeting and write down all the questions you want to ask the doctor. This will ensure that you do not forget any important points during the conversation and the doctor can find the best treatment. Remember to send any necessary documents or health data to the doctor before the meeting (if needed). This will help your doctor understand your problems better.

(2) Find a suitable place before the appointment, where you have a good internet connection and free of noise and disturbances.

With these simple guidelines, you will be able to tele-consult your doctor for health advice. Your doctor can then make a diagnosis and prepare a treatment plan for you. This may include prescribing medication, ordering further tests, or referring you to a specialist. If more tests are needed, it is important to be able to understand the results. Find out more about this topic on the following pages.

Do you wish to improve your eHealth skills? Here you can find information and/or education offers in your country:

https://gesund.bund.de/gesundheitskompetenz-digital-staerken#angebote

https://dngk.de/verlaessliches-gesundheitswissen/#gesundheitsportale

https://digivitaler.nl/

https://helpdeskdigitalezorg.nl/

https://www.dgs.pt/documentos-e-publicacoes/manual-de-boas-praticas-literacia-em-saude-capacitacao-dos-profissionais-de-saude-pdf.aspx

https://www.splsportugal.pt

https://ehealthromania.com/

https://spatiulmedical.ro/categorie/e-health/

https://www.groupama.ro/ghiduri/telemedicina/

https://pydesalud.com/recursos-sobre-la-alfabetizacion-digital-sanitaria/

There are a variety of health tests that target different aspects of health. Common types of health tests include blood glucose tests, blood count tests, blood pressure monitors, pregnancy tests, drug tests, COVID-19 tests, and HIV self-tests. However, the results of these tests can seem like a maths exam.

Here you will find an explanation of common testing methods, and helpful links and guidelines that explain how to read medical test results for different medical conditions.

How health tests work

There are two different ways in which health tests are analysed. Knowing this may help you understand the results of the test a little better.

Normal range analysis - Laboratory values can vary greatly depending on gender, weight, age and lifestyle, even in healthy people. To take such variations into account, experts have defined so-called normal ranges or reference ranges. Within these ranges lies the vast majority of the values measured in healthy people. If your test result lies within these ranges, it is considered unremarkable or normal. On the other side values can be called remarkable or abnormal, if they fall outside of the normal range. This technique is for example used in blood count tests.

Dichotomous analysis - A much simpler method of evaluating health tests is the distinction between positive (the person is ill or has the pathogens) and negative (the person is uninfected and has no pathogens). The results of these tests are much easier to understand. This method is used, for example, for COVID-19 and HIV self-tests.

Guidelines for understanding different health tests

Below you will find an overview of common health tests with a short description on how they work and what they measure.

Blood count test

A blood count test looks at the composition of the blood and is one of the most common tests. It gives an overview of the cells in the blood: red blood cells, white blood cells, platelets and red blood pigment. Among other things, the values can indicate inflammation, anaemia, nutrient deficiency, or an infectious disease.

Blood glucose test

A blood glucose test measures the glucose level in your blood. Glucose is a type of sugar that is your body's main source of energy. The test helps measure the level of a hormone called insulin, which is responsible for transporting glucose from the blood into the cells. The test is mainly used to detect diabetes or pre-diabetes.

Blood pressure test

Blood pressure is the level with which the blood is pressed against the walls of your arteries. The arteries transport blood from the heart to other parts of the body. Your blood pressure usually rises and falls throughout the day and the higher it is, the greater your risk of health problems such as heart disease, heart attack and stroke.

Electrocardiogram test

An electrocardiogram (ECG) is a simple, painless and quick test that records the electrical activity of your heart. Every time your heart beats, an electrical signal is passed that causes the four chambers of your heart to contract (squeeze) in the right rhythm. This helps your heart pump blood around your body. An ECG scan helps diagnose and monitor many types of heart disease and their treatment.

HIV-test

An HIV test is usually a test that identifies antibodies against HIV in your blood. Antibodies can be detected with a laboratory test at the latest six weeks after infection, with a rapid test at the latest after twelve weeks. An HIV test is recommended if you had unprotected sex with someone.

COVID-19 test

COVID-19 tests are a simple method to check if you have corona. You can do a rapid self-test at home (an antigen test), or go to a medical facility to get a more accurate PCR test. A positive test indicates that you have corona. Check your country's regulations for the current recommendations about what to do when you are infected.

3D imaging

In some cases test results may include 3D images, such as special 3D MRI's, CT scans, or ultrasounds. These new technologies may be difficult to understand at times, but it is important to realise that they give a better representation of what our bodies actually look like, and will therefore help a specialist better understand the issue at hand.

For more information on health tests and results in your country, check out the links below:

https://www.stiftung-gesundheitswissen.de/gesundes-leben/koerper-wissen/laborwerte-richtig-verstehen/

https://www.apotheken-umschau.de/diagnose/laborwerte/

https://www.rivm.nl/gezondheidstesten/uitslag

https://labuitslag.nl/

https://www.sns24.gov.pt/servico/resultados-dos-exames-eletronicos/

http://www.mymed.ro/analize-medicale-explicate-pentru-pacient-ghid-de-interpretare-a-analizelor-uzuale1.html/

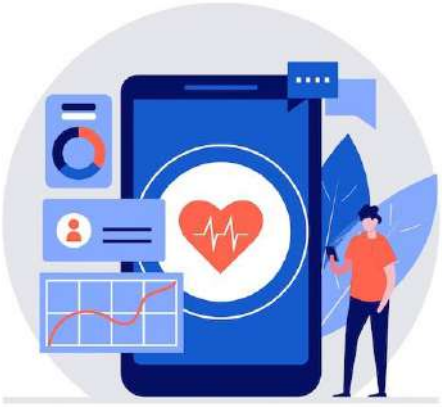
https://www.csid.ro/analize-medicale/

https://muysaludable.sanitas.es/salud/interpretar-analisis-sangre/

1.2 Health Records: Usage and data security

What are Health records and which types exist?

The use of Health Records is increasing in Europe, with many countries looking to modernise their healthcare systems and improve patient care using digital health technologies. Health records provide a central place for patients and healthcare providers to store and access health data digitally. Here you will find a description of the two common forms of health records:



Electronic Health Records (EHRs) are digital records of patients' medical history, treatment plans, test results, prescriptions and other health-related information. EHRs are typically created and managed by healthcare providers and organisations such as hospitals or clinics and are used to store and share patient information among different healthcare professionals.

Personal health records (PHRs), contain the same information as EHRs, but are managed and controlled by patients themselves. PHRs are updated by patients themselves or with the help of their healthcare providers. PHRs are designed to empower patients by giving them more control over their health information and enabling them to better manage their own care and share information with their healthcare providers.

Health Records in your country

How personal health information is accessed and shared differs per country. Below you will find an overview about health records and data security in each TRIO partner country (Germany, the Netherlands, Portugal, Romania, and Spain). Here you can find which health record solution is used, through which portal you can access it, and how data security is assured.

GERMANY

Health Record solution: Since the beginning of 2021, Germany has had the so-called *Elektronische Patientenakte* (ePA), which can be seen as the first major advance towards a digitalised healthcare system. Since then, patients have the right to have such a file created electronically by their health insurer, although keeping such a file is not obligatory. Patients must also fill their records with data themselves. This includes examination findings, diagnoses or doctor's letters. Data that is not available digitally must be converted into digital form by the patients themselves by scanning or photographing it. Also, the patients themselves determine which data they want to disclose to which actor and which data will be deleted.

Portal to access your Health Record: The ePA is created by the health insurance companies at the request of the patients. The exact portal you can use to manage your health record therefore depends on your insurance company. In the link below you can find out which portals are available for which insurance.

- https://www.gematik.de/anwendungen/e-patientenakte/epa-app/

Data security: If a treating physician wants to receive information about a patient, he or she does not have automatic access to the respective ePA. Access must always be authorised by the patients themselves. This is done by assigning a PIN, which can be used by the treating person to activate the ePA. For example, the patient's health insurance company may not simply access the data and the patient can also set only partial access to data. This is to prevent the misuse of health data, even though it is time-consuming for the patients. This is at the same time a big point of criticism. Even though the system has been in existence for almost two years, it is still largely unknown to people. Only a small part of the population is knows about the existence of this service, which is why very few are already familiar with information on how to handle or protect data within health records.

THE NETHERLANDS

Health Record solution: In The Netherlands Medical information is stored in a personal electronic health record at someone's GP practice and apothecary. Everyone has the right to view their own health record, correct errors, and request information to be deleted. Medical data can exclusively be accessed by other healthcare practitioners and only if this is needed for a treatment.

Portal to access your Health Record: Since July 1 2020, it is possible for all Dutch citizens to view their medical data online. This can be done in two ways: through a patient portal or through a personal health environment (PGO). A patient portal is a secure website or app from a specific healthcare provider, for example a GP. Here, people can view, for instance, their own medical file, make appointments, order medicines, receive medical results and ask questions to a healthcare professional. Which patient portal is used depends on the healthcare provider. This is often indicated on their website.
A personal health environment (PGO) is a secure website or app in which medical data is collected from multiple care providers, for example a GP, the hospital and the physiotherapist. This gives a better overview. Patients can also add data themselves, such as blood pressure values or non-prescriptions drugs. Patients can choose a PGO themselves, but not all healthcare organisations are currently connected with a PGO. Although the number of caregivers who support this is increasing. For more information and to see if your caregiver has access to a PGO, check out the link below:

- https://www.pgo.nl/

The Netherlands also has a healthcare infrastructure called '*het landelijke schakelpunt*' (LSP). The LSP is a secure network that healthcare providers can connect with to share medical information. The LSP however is not a database; medical data is not stored there. The GP can sign up a patient's citizen service number (BSN) at the LSP, which will then be stored in a referral index. By searching a patient's BSN a healthcare practitioner can access the medical information that has been made available to them.

Data security: Medical data from patients records can exclusively be accessed by other healthcare practitioners and only if this is needed for a treatment. Any other medical information can only be shared after explicit permission from the patient. Insurance companies cannot access personal medical data.

PORTUGAL

Health Record solution: In Portugal, medical information is stored from each citizen in their Electronic Health Record (EHR) in order to improve healthcare delivery. In the EHR healthcare professionals can register and share health information between the patient, other healthcare professionals and entities providing health services.

Portal to access your Health Record: Citizens can access their health record through the SNS 24 platform. In the Personal Area of the platform, each citizen has access to his/her medical data including consultations, prescriptions, surgeries, exams, the COVID-19 digital certificate, and medical history. It is also possible to grant or change permission on who can access the information.

- https://www.sns24.gov.pt/

Data security: The Portuguese EHR solution is secure according to the requirements of the National Commission for Data Protection.

Health information encompasses a range of data associated with a person's health, including clinical records, medical history, test results, treatments, and diagnoses. Health information belongs to the person to whom it relates. Generally, individuals have the right to access all their health information, with rare exceptions where access could seriously harm their well-being. In the case of a deceased individual, a family member may access their health information if they can demonstrate a direct, personal, legitimate, and relevant interest, such as for legal actions or protecting their rights.

ROMANIA

Health Record solution: Although a law from August 2018 provides the legal framework for the implementation of the patient Electronic Health Record, the only existing version of the Electronic Health Record at a national level has been released in November 2021 as a test environment. This version only implements a section related to "emergency medical data". In the absence of a national health information system, medical information of patients in Romania is digitally stored in a fragmented way, in the local health records of the healthcare providers. Patients are responsible themselves for keeping track of their information and to bring copies (e.g. paper copies of blood test results, CDs/DVDs of CT scans, etc.) of their medical data.

Portal to access your Health Record: Citizens can access their health record through the National Electronic Health Record portal. However, the portal has been recently deployed and its usage and data availability depends on the degree to which your family doctor is actually using it, as it is not yet mandatory for the public healthcare providers to use it. The access to the online personal health record is only possible once the family doctor has initiated the record.

https://ehr.des-cnas.ro/cnasportalext/index.html#/acces/

Data security: The personal data of the patients are secure and protected according to The National Supervisory Authority For Personal Data Processing.

https://www.dataprotection.ro/

SPAIN

Health Record solution: In Spain the healthcare system is decentralised to the 17 autonomous regions. Each region has the authority to establish their own healthcare system, while the State keeps control over the establishment of the bases and overall coordination of health issues. In 2007 was decided that a common EHR system was needed to enable the exchange of data between regions. This is system is called the *Historia Clínica Digital del Sistema Nacional de Salud* (HCDS).

Portal to access your Health Record: Users can access their medical data through the website of the health service at which their health card is registered. These medical portals vary per region, but can include functions like consulting your GP, arranging and managing medical appointments, and accessing your medical history, including test results, treatments, information on allergies, active and previous episodes, previous instructions, vaccinations, alerts, diagnoses, blood type, and prescriptions.

Data security: The identity of both users and professionals needs to be verified before they can make use of the HCDS system. The responsibility for this lies with the regional authorities. Citizens can monitor which instances have access to their data, so they can verify their legitimacy. Citizens have the right to limit access to part of their data to professionals that don't normally treat them. However, data cannot be deleted from their record and professionals that access the file will be made aware that some information is hidden.

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